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13. ABSTRACT (Maximum 200 Words) The U.S. Medicine Institute for Health Studies, a nonprofit entity devoted toward enhancing communication among federal agencies and between federal agencies and the private sector, conducts forums and smaller roundtable discussions at which high-level officials engage in frank discussion of issues of current import to federal health programs. During 2004, the Institute addressed these issues: the value of long-term studies (forum); healthcare for reserve forces (roundtable); mental health services for veterans (roundtable); and the future beyond the electronic health record (roundtable). Results of those discussions are presented in this report. Results are disseminated to key federal and congressional offices and made available on the U.S. Medicine Institute for Health Studies website: www.usminstitute.org .				
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Table of Contents

Introduction	1
Body	2
Key Accomplishments	16
Conclusions	17
Appendix	18

Introduction

The technology and policy issues that often complicate healthcare research and delivery can benefit from frank, candid discussion among key officials and observers in both the federal and private sectors. The U.S. Medicine Institute for Health Studies (USMI) brings these individuals together to examine topics of current import and arrive at suggestions for future collaboration and action.

Body

The U.S. Medicine Institute for Health Studies (USMI) is a nonprofit organization (501c3) that promotes analysis, interaction and debate on critical issues in medicine and healthcare. USMI's mission is to provide an objective setting in which officials from federal agencies, academia and the private sector can engage in candid discussion and develop a blueprint for progress on a particular topic.

USMI operates under the belief that federal agencies offer a "laboratory" for health care policy, research and practice that can impart benefits to each other, to the private sector and to the nation as a whole.

USMI fulfills its role as an unbiased convener of discussion through:

- *Forums for decisionmakers.* These invitation-only events bring together a spectrum [80 to 100] of prominent federal, business and academic healthcare leaders in a format designed to inform, to stimulate discussion and to attain consensus.
- *Round-table discussions.* These smaller events [25 to 30] are designed to allow more detailed discussion of relevant issues among high-level officials.
- *Executive Leadership Program.* This program for emerging leaders brings them together with senior mentors to study leadership principles and issues through questioning and dialogue.

Topics for USMI programs are suggested by federal officials, sponsoring organizations and/or USMI's advisory committee [see Appendix].

The discussions which take place during USMI's forums and roundtables are transcribed; an executive summary and edited transcript are made available

to key federal, congressional and private-sector officials. In addition, these reports are published on the USMI website at www.usminstitute.org.

From March 1, 2004, through February 28, 2005, USMI programs addressed long-term studies, healthcare for reserve forces, mental health services for veterans, and the future beyond the electronic health record. In each case, frank, candid discussion led to recommended actions and calls for increased collaboration between federal agencies, as well as with the private sector. Addressing issues in an unstructured, yet moderated setting allows officials to partake of each other's viewpoints without a requirement for defined action. Free exchange of ideas is encouraged.

For example, the USMI forum on the value of long-term studies elicited extensive debate on the feasibility and desirability of continuing the Air Force Ranch Hand Study and suggested that tri-service longitudinal studies be coordinated through the Uniformed Services University of the Health Sciences. The roundtable discussion on healthcare for reserve forces brought forth discussion cautioning that readiness must be the primary consideration in any attempt to restructure health benefits for members of the Guard and reserve. During the roundtable on mental health services for veterans, there was agreement that a "recovery" model is the desired approach in dealing with potential combat stress reactions in the growing number of veterans of the conflicts in Iraq and Afghanistan. The roundtable on the future beyond the electronic health record was marked by recommendations that the electronic health record (EHR) become a visual rather than textual document that relates the story of an individual's medical history and status. Concern was expressed that the EHR be developed into a means of enhancing prevention and incorporating a rapidly increasing array of new technologies, such as virtual reality, image mapping and robotics.

Following are the detailed summaries of those USMI events.

Executive Summary — USMI Forum for Decisionmakers

Taking The Long View: The Value of Studies Over Time

Washington, D.C. March 4, 2004

Long-term studies help answer specific questions about health risks and consequences over time and often deliver byproducts not originally envisioned but with ongoing, exponential value. Consequently, long-term studies are essential for informed policymaking and provide liberal return on the substantial investment they entail.

These were the views interwoven throughout a forum held on March 4, 2004, by the nonprofit **U.S. Medicine Institute for Health Studies**. The consensus among panelists and participants was that long-term studies undoubtedly deliver great benefit to society at large, as well as to the specific group or groups targeted in a particular protocol. For example, the 22-year-old Ranch Hand study of agent orange exposure in Vietnam offers a trove of longitudinal data on the aging process in men— with much of this data yet to be tapped.



Forum deliberations found long-term studies of such value in answering questions relating to public health that they should become a byproduct of how “we normally do business” in healthcare — especially as digital patient records make collection and analysis of data amenable to routine analysis.

These edited proceedings present the remarks of panelists at the forum and the ensuing discussion among participants. Observations presented during the group’s deliberations include:

- Long-term studies are essential for the understanding of disease and, consequently, for disease management. They give policymakers the data and findings needed to make rational determinations about eligibility for compensation relating to occupational exposures.
- As long-term studies are done in future, they should be accompanied by “clear” business case analyses, “so that there really is a clear understanding of the rewards that come from the ... investment in conducting these studies.”
- As disease patterns among Americans shift away from the acute toward chronic, multiple conditions, long-term studies will assume a greater role, because they allow

examination of particular populations and pick up a “different set of information” about risk factors than short-term clinical trials can.

Decades-long studies such as the Framingham Study that delineated risk factors in heart disease and the Harvard Nurses Study of risk factors for major chronic diseases in women are well-known examples of the importance that long-term investigations can have in shaping health practices and policies.

- Long-term studies conducted by federal agencies need the stability afforded by designated funding, rather than having their funds come through basic agency appropriations.
- The Veterans Affairs and Defense departments use long-term studies to help answer questions about potential deleterious health effects in troops from exposures during deployments — questions now anticipated for every deployment: Who was exposed; are those exposed showing unusual disease; are those exposed dying at unusual rates or from unusual causes, or has their health changed over time; do those exposed show higher incidence of cancer(s); do the children of those exposed exhibit higher rates of birth defects?
- A classic longitudinal study is the Air Force Ranch Hand Study, initiated in 1982, which has seen the collection of 74,000 biological specimens and 19,000 x-rays and has involved more than 13,000 physical exams, more than 20,000 questionnaires and thousands of records on conception and birth. In addition, more than 2,800 death records have been obtained.

This study is scheduled to terminate in 2006, but that directive has met with controversy on grounds there is much information yet to be mined. To resolve whether the study should be continued, Congress has asked the Institute of Medicine to examine the scientific merit of retaining and maintaining the medical records, specimens and other data collected for the study; the potential value of extending the study; and the advisability and costs of making study specimens available to independent researchers.

- An important longitudinal study that is just beginning in the military is the Millennium Cohort Study, which involves an initial study group of 10,000, with 20,000 more to be added this year and another 20,000 to be added in 2007. The study will examine employment exposures and post-deployment consequences in a group exposed in Kosovo or Southwest Asia, compared to a nonexposed cohort.

Study participants will be followed every three years by postal surveys; demographic and health information will be obtained and correlated over a 22-year period.

- The Veterans Affairs Department regularly turns to the Institute of Medicine for objective, independent literature reviews of the long-term effects of exposure on troops

— for Vietnam, for the first Gulf war and for the current Iraq conflict, for example. Results are used to help set compensation policy.

- Tri-service longitudinal studies might best be centralized and coordinated through the Uniformed Services University of the Health Sciences, which encompasses all service branches as well as the U.S. Public Health Service.
- Doing longitudinal studies often is difficult in the academic setting, where there is pressure for immediate pay-off. At the same time, studies produced by federal researchers all too often are rejected by regular scientific journals as being of limited interest because they focus on military or veteran populations.

This forum was moderated by Susan H. Mather, MD, MPH, of the Department of Veterans Affairs. Panlists were Mark Brown, PhD, of the Department of Veterans Affairs; Michael Stoto, PhD, of Rand Corp.; David Tornberg, MD, MPH, of the Department of Defense; Robert Graham, MD, of the Agency for Healthcare Research and Quality; Rick Erdtmann, MD, MPH, of the Institute of Medicine; and Lt. Gen. James Peake, MC, USA, Army Surgeon General.

Executive Summary — USMI Roundtable Discussion

Healthcare For Reserve Forces: Examining The Issues

Washington, D.C. May 24, 2004

Reserve forces play a major supporting — and sometimes starring — role in U.S. military operations, leading to concern that their health benefits ought to mirror those provided to active-duty personnel, but also raising questions about the proper level of benefits for reservists before and after activation, the costs inherent in increasing reserve healthcare benefits, and the potential impact on the attractiveness of active-duty versus reserve service.

To examine these issues, the nonprofit **U.S. Medicine Institute for Health Studies** convened a roundtable discussion among federal agency, private sector, congressional and beneficiary group representatives, all of whom agreed that reservists called to active duty should have benefits on par with those provided to the regular active-duty force. The difficulty arises, they agreed, in trying to craft an enhanced benefit for reservists pre- and post-activation. The group urged caution in devising a richer benefit that would shift coverage-costs from the private to the federal sector, incur mounting budgetary obligations in succeeding years, and potentially have little impact on recruitment and retention or readiness. **Readiness**, discussants emphasized, must be the prime consideration in any examination of the reserve benefit structure.

Background

Reserve forces today constitute a higher percentage of deployed troops than any time since the Korean War, serving in such trouble spots as Iraq, Afghanistan and Bosnia. More than 320,000 reserve and guard personnel have been activated since the September 11, 2001, attacks on the United States. In fiscal 2004, reservists will serve 60 million man-days, compared with 15 million in the late 1990s.

Members of Congress in particular are concerned that the increasing defense burden borne by reserve forces ought to be accompanied by parity in health benefits provided to active-duty personnel, and both the House and Senate are in the process of legislating an enhanced health-benefit package for reservists. But, what would be the true impact of such an increase in the health benefit?

Roundtable Discussion/Consensus

Roundtable discussants noted that 80 per cent of reservists already have healthcare

insurance through their employers. The 20 per cent without private insurance largely are young, healthy individuals who decline to spend money on health premiums and would be unlikely to be swayed by a richer premium-based federal health benefit for reserve forces. The greater concern among troops, discussants agreed, lies in such issues as having a sufficient level of skills and requisite equipment and body armor for dangerous deployments — areas in which additional resources might draw greater returns in terms of force readiness, and recruitment and retention, than would a richer healthcare benefit. Reservists are not clamoring for an enhanced federal healthcare benefit — but they are concerned about access to disability payments should they be injured while on active duty, discussants pointed out, observing that disability concerns often are mistakenly interpreted in Congress as a demand for greater health benefits.

Discussants reiterated throughout the roundtable that **readiness** must be the prime consideration in any enhancement of benefits for reservists. Current efforts to extend federal health benefits to inactive reservists should focus on the transition period both pre- and post-deployment: pre-deployment, to make sure reservists are healthy and fit for active duty, and post-deployment, to make sure reservists receive needed care for any injuries received during activation (the disability concern). The Defense Department, Veterans Affairs Department, Congress and beneficiary groups should work together to determine the optimum length and richness of such transition benefits, which now are provided on a limited basis through a TriCare demonstration program and through the VA system.

Should the political push for “equity” between inactivated reservists and active-duty personnel reach fruition, there might be less incentive for anyone to join the active forces, discussants cautioned. Should the full TriCare benefit be offered to inactive reservists, employers in most cases would try to shift their employees who belong to the reserves to the federal program, thus reducing their corporate health insurance costs. The result of this would be a greatly expanded federal financial obligation that would exceed “what this country can afford.”

Some in the group suggested that reservists should be divided into subsets, with enhanced benefits designed especially to retain those with certain skills and training. However, it was decided, identifying these subsets would be extremely difficult under current data-analysis capabilities.

Among the observations made during the roundtable:

- There is a simple way for reservists to have health benefits that are the same as those given to active-duty personnel — become part of the regular active-duty force. “We are in danger of making the manpower piece cost too much and enhancing the benefit beyond what we can afford.”
- Reservists signed up voluntarily for their potential activation and bear some

responsibility to keep themselves ready for deployment.

Participants in this roundtable: Ed Wyatt of EWyatt Consulting, moderator; Rick Stark of the Center for Strategic and International Studies and Patty Lewis of Monfort-Lewis LLC, discussion leaders; Dave Baker of Humana Military Healthcare Services, Cindy Bascetta of GAO, Ben Butler of NAUS, Marcia Crosse of GAO, Craig Duehring of DoD, Kenneth Farmer of the Army, Lynn Henselman of the House Armed Services Committee professional staff, Brian Hurley of Edward Martin & Associates, Michael Kussman of the VA, Steve Lillie of DoD, Steve Mirick of AMSUS, Bob Norton of MOAA, Ron Richards of DoD, Sue Schwarz of MOAA, Wayne Spruell of DoD, Harley Thomas of PVA, Charlotte Tsoucalas of Defense Health Advisors, Debra Wada of the House Armed Services Committee professional staff, Bob Washington of the Fleet Reserve Association, and Kathleen Woody of the Army

Executive Summary — USMI Roundtable Discussion

The Changing Face Of Mental Health Services In The Veterans Health Administration

Washington, D.C. October 18, 2004

As military operations in Iraq and Afghanistan produce an increasing number of veterans at risk of symptoms related to combat stress, questions have arisen as to how best to move services offered these returning warriors to a “recovery” model that engages affected individuals in their own care, at the earliest stage possible, and reduces anxiety over stigmatization. At the same time, the current disability compensation system for veterans is seen as outdated when it comes to mental health symptoms and in conflict with the desired focus on recovery.

To examine optimal changes in mental health services for veterans, the nonprofit U.S. **Medicine Institute for Health Studies**, in partnership with the Veterans Health Administration (VHA), convened a roundtable discussion among federal agency, congressional and beneficiary group representatives. A major recommendation emerging from the group’s deliberations urges joint policy discussions on how best to change the disability system so that it incorporates the principles of “recovery” and shifts its current “adversarial” nature to one of greater support for achieving wellness.

Background

One-fifth of veterans use specialized mental health services provided by VHA, and 22 to 29 per cent of veterans exhibit substance abuse disorders — the two leading causes of disability among veterans. A study in the *New England Journal of Medicine* of troops returning from operations in Iraq and Afghanistan found that only 23 to 40 per cent of those who, upon screening, reflected mental health symptoms actually sought care. The study’s military authors conclude that while returning troops are at significant risk of stress-related mental health problems, “subjects reported important barriers to receiving mental health services.” Of prime importance, they said, was concern about the “stigma” attached to seeking mental health care.

The current influx of combat veterans from Southeast Asia occurs against a background of more general interest in improving mental health services. The President’s New Freedom Commission on Mental Health Services, on which VHA was represented, issued a report in 2003 calling for an approach emphasizing early detection and treatment, incorporated into primary medical care.

Roundtable Discussion/Consensus

Roundtable discussants pointed out that the all-volunteer operations in Iraq and Afghanistan differ from previous conflicts in that a much higher percentage of combat troops are in the Reserve and National Guard; more women are deployed; and more troops are married. These new demographics present challenges for mental health care. For one thing, Guard and Reserve personnel return to their local communities, where the network of care available to those who remain on active duty does not exist. Discussants questioned the value of current programs that screen troops immediately before or after redeployment to the U.S., since mental health symptoms often develop months or even years after return.

Programs that are "paternalistic" and do not involve veterans in their own therapy are not effective, the group agreed. VHA recently was given authority to hire 50 veterans of the Southwest Asia conflicts to reach out to their peers, and this has proven a successful approach – with the added benefit that these veterans have educated VA staff about how to reach out with mental health care. More such programs are needed, the group advised.

Of significant concern to the group was the current disability compensation system: Veterans fear losing their disability payments and thus have little motivation to engage in activities that help them recover. Discussants suggested that a joint VA/Defense Department/congressional group be assembled to develop recommendations for the VA secretary on how the current system can be made to support the recovery model and "reward" wellness.

The group also recommended that VA and DoD jointly address the stigma attached to seeking mental health services. Returning troops often do not acknowledge stress-related symptoms during screening because they fear they will lose respect among their peers and do not want to do anything that might delay their return home. It is essential, discussants said, that troops and families be educated to watch for symptoms months after the individual has returned, with six months the time at which such symptoms develop most frequently. The ideal, the group agreed, would be to move from screening to ongoing monitoring.

Among the items highlighted during the roundtable:

- Recovery is a journey of self-healing that allows the individual to regain a sense of self and a role in society. The recovery model integrates peer support and family education as essential ingredients and recognizes the mental health problems are social as well as biologic. Medical professionals need more education in the concept of recovery.
- VHA's vet centers have proven "ahead of the curve" in fostering peer-to-peer relationships for those with combat stress disorders. The best way to overcome concerns

about stigmatization is through person-to-person contact with someone who has recovered.

- In addition to post-traumatic stress, other types of mental health disorders are appearing in veterans from Iraq and Afghanistan, including a sexual trauma and an increasing rate of homelessness.

Participants in this roundtable: Frances Murphy of VHA, moderator; Al Batres of VHA and Dan Fisher of the National Empowerment Center, presenters; John Barilich of VHA; Alan Bellack of VHA; Fred Blow of VHA; John Bradley of DoD; John Bradley of the House Committee on Veterans Affairs; Steve Cavicchia of VHA; Stephen Cozza of DoD; Gerald Cross of VHA; Pete Dougherty of VHA; Anita Everett of SAMSHA; Gretchen Haas of VHA; Patricia Hayes of VHA; Sherrie Herendeen of VHA; Ira Katz of VHA; Michael Kussman of VHA; Bruce Levine of VHA; Miklos Losonczy of VHA; Susan Mather of VHA; Theodore Nam of DoD; Harold Wain of DoD; Terry Washam of VHA; Cathy Wiblemo of the American Legion; and Antonette Zeiss of VHA.

Executive Summary — Roundtable Discussion

Beyond The Electronic Health Record: Anticipating The Direction Of Future Technologies

Washington, D.C. December 6, 2004

Technologies exist today that can change the electronic health record (EHR) from a “passive archive” to a highly effective interactive tool for healthcare providers, patients and policymakers, and exciting advances in such areas as robotics and virtual reality continue to jump from the drawing board into demonstration testing at rapid pace. Yet, alongside this exciting stream of innovation in healthcare informatics has been reluctance within the medical sector to adopt even a basic EHR.

This reluctance now is being challenged by the federal government in a concerted effort to standardize, certify and encourage growth of the EHR through new incentives and federal-private partnerships. To examine how to anticipate the best future goals for the EHR as it undergoes this desired evolution, which continually must incorporate new technologies, the **U.S. Medicine Institute for Health Studies**, in partnership with the **DARPA Advanced Biomedical Technologies Program**, convened a roundtable discussion among federal agency, congressional and private-sector representatives. The group emphasized it is essential that EHR be “inter-operative” with other data sources and be able to incorporate new technologies as they develop, so that it truly can become an “enabler” of more cost-effective care and a healthier population.

Background

Man and machine lead a symbiotic existence, producing a whole that is greater than either part. While this reinforcing relationship is well recognized in most aspects of American society, from computer gaming to financial transactions, the healthcare sector has been slow to adopt digital technologies and largely continues to rely on a paper record of diagnoses, treatments and outcomes.

Now, however, there is financial and policy stimulus by the federal government to promote standardization and widespread use of the electronic health record (EHR), building on the few health systems, such as that of the Department of Veterans Affairs, already using an EHR extensively and effectively. As the EHR gains greater momentum, questions about its optimum structure and connectivity have intensified: How should data from the many different care delivery sites and devices a patient may encounter — as well as everyday factors, such as stress levels, pollution exposure, diet — be fed into the

EHR; how can data be arrayed so disease trends are detected over time and “best practices” developed?

Summary of discussion

The medical record changes every 50 to 70 years, and the group stressed that current efforts to develop the EHR should make it sufficiently adaptable to endure for such a lifespan rather than become obsolete once fully developed. Healthcare is the only sector of the economy without a virtual representation of its product, yet there are modeling and robotic technologies currently extant that can feed into a “holomer,” that is, a virtual representation of the individual. The “holomer” is a desired format for the EHR, which should developed such that it is a visual rather than a text-based tool.

Initial steps in developing such a “holomer” are being taken. For example, the Armed Forces Institute of Pathology is doing total body scans on military personnel killed in Iraq to provide critical data on wound tracks and effects. Such total body scans can provide individuals a baseline of health status against which future changes can be measured.

Among the other issues addressed during the roundtable discussion:

- A patient record is the life-story of that individual, yet the technology for reading that story remains disjointed. New generations of “computer-savvy” providers should help move the EHR toward being a visual story that develops over time, rather than fragmented pieces of text and images. The story must be presented in a compelling manner, akin to a TV program.
- The EHR must be a training and assessment tool that can help both novice and seasoned professionals “practice” and perfect procedures and treatments before they are delivered.
- EHR robustness will come via the intersection of technologies — engineering, biology and data processing. For example, radio frequency identification (RFID), image analysis, and computer-interpreted situational awareness are migrating from industrial to medical application. “Smart” prostheses can be operated by brain signals, cancer can be diagnosed through shape comparisons, and robotic surgery can be accomplished in super-sterile environments with the surgeon seated at a computer console.
- Ethical and moral issues will accompany the continuing development of the EHR — genetic engineering, body parts replacement, extending longevity, artificial intelligence — and they must be addressed.
- Patient demand will help prompt the medical profession to embrace the EHR. At the same time, there are consumer concerns that must be acknowledged. For example, some pilots in the Iraq conflict removed data chips encoding their health status from

- identification cards for fear the information would be useful to their captors, should they fall into enemy hands.
- The EHR should be preventive and proactive. It must include the patient in a partnership that is interactive and internet-based.

Participants in this roundtable: James A. Zimble, Past President, USUHS, moderator; Richard Satava of the University of Washington and DARPA, David Brailer of HHS, Jim Miller of GE Reseach, Alexander Tsiaras of Anatomical Travelogue, and Tim Ganous of the University of Maryland, presenters; Cindy Bascetta of GAO; James Bengel of DoD; Ronald Blanck of the North Texas University Health Science Center; Linda Fischetta of VA; Cliff Freeman of VA; Bart Harmon of DoD; Janet Heinrich of GAO; Janice Lee of DoD; H. Stephen Lieber of HIMSS; Lance Manning of DARPA; Ron Pace of the Army Medical Research and Materiel Command/TATRC; James Peake, former Army Surgeon General; Hank Rappaport of VA; Pedro Rivera of Health Net Federal Services; William Rowley of the Institute for Alternative Futures; Diane Thompson of FasterCures; Margaret Van Amringe of JCAHO; Julie Wands of the Bureau of Prisons; Kathleen Weldon of the House Ways and Means Committee; and Michael Zamore of Rep. Patrick Kennedy's office.

Key Accomplishments

Through its series of forums and roundtables, the U.S. Medicine Institute for Health Studies fosters dialogue and collaboration. The results of these discussions are used to help shape agency policies, forge new alliances and address issues in healthcare.

Technology issues addressed include the need for a stable Electronic Health Record that incorporates recent advances such as robotics, virtual reality and image mapping. The EHR should be a continuous story, rather than piecemeal, and thus must be an integral part of medical care, and especially of prevention.

Enhanced collaboration between the Veterans Affairs and Defense departments, congressional staff and private organizations was developed during discussion of the need for more realistic treatment for troops returning with combat stress from the operations in Iraq and Afghanistan. There was agreement that recovery should be the ultimate goal, with education essential for veterans and their families.

Discussion of healthcare benefits for reserve forces brought concern about the rapidly increasing role of the Guard and Reserve in combat operations. The profile of the force structure is changing, but benefits for reservists may not necessarily need to be as rich as those for the active force, since many Reserve and Guard members have private insurance coverage. There is need to find the proper line — while keeping readiness the ultimate purpose — in redefining benefits to fit the new force profile.

The issue of the value of long-term studies brought consensus that such studies are essential for informed policymaking but must be accompanied by business-case analyses, so there is clear understanding of the rewards that come from investment in such studies. A stable funding mechanism is needed for long-term studies. A longitudinal study suffers when year-by-year appropriations continually question its value or threaten its continuation.

Conclusions

Important and portentous healthcare issues that involve both the federal and private sectors can be successfully examined — with progress resulting — through candid discussion among high-level officials.

Federal agencies often are at the forefront of issues that affect all healthcare sectors and can serve as a “laboratory” for addressing these issues.

Appendix

USMI Board of Directors

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USMI Advisory Committee

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